DOCUMENT RESUME

ED 411 663 EC 305 856

AUTHOR	Kennedy, Jae; LaPlante, Mitchell P.
TITLE	A Profile of Adults Needing Assistance with Activities of Daily Living, 1991-1992. Disability Statistics Report 11.
INSTITUTION	California Univ., San Francisco. Inst. for Health and Aging.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	1997-06-00
NOTE	48p.; For report number 10, see ED 409 699.
CONTRACT	H133B30002
PUB TYPE	Numerical/Quantitative Data (110) -- Reports - Research (143)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Adults; Age Differences; *Daily Living Skills; *Disabilities; *Eligibility; Evaluation Criteria; Helping Relationship; *Independent Living; Low Income; *Participant Characteristics; Social Services; *Trend Analysis
IDENTIFIERS	*Personal Assistance (of Disabled)

ABSTRACT

This report uses data from the 1990 and 1991 samples of the Survey of Income and Program Participation to construct a profile of the U.S. noninstitutionalized adult population needing assistance with activities of daily living (ADL) and to estimate the size of the population eligible for federal personal assistance services (PAS) under different ADL, income, and age criteria. It also describes current sources of ADL assistance by recipient type. Research results indicate that an estimated 7.3 million noninstitutionalized adults are limited in their capacity to perform one or more of five basic ADLs (bathing, transferring, dressing, eating, toileting), and some 3.7 million require the assistance of another person in performing ADLs. The report concludes that: (1) roughly 1.4 to 2.2 million adults would be eligible for a federal personal assistance benefit under basic ADL criteria; (2) means-testing has a very large effect on total program eligibility counts; (3) younger adults with disabilities constitute over one-third of the adult population needing ADL assistance; (4) a significant proportion of ADL limitations appear to be short-term; (5) most people with ADL assistance needs get help from family members; and (6) ADL assistance requirements are useful in delimiting categories of need. (Contains 75 references.) (CR)

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REPORT 11

Disability Statistics Report

A Profile of Adults Needing Assistance with Activities of Daily Living, 1991-1992

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A PROFILE OF ADULTS NEEDING ASSISTANCE WITH ACTIVITIES OF DAILY LIVING, 1991–1992

by

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June 1997

Prepared with funding from the
National Institute on Disability and Rehabilitation Research,
U.S. Department of Education, under award number H133B30002.

ACKNOWLEDGMENTS

This report was supported by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. Sean Sweeney was the project officer. The authors would like to acknowledge the substantial contributions of Teh-Wei Hu, Meredith Minkler, Jack McNeil, Stacy Furukawa, Ed Yelin, and Laura Trupin in the development and production of this analysis. Steve Kaye edited the manuscript and Kathleen Rudovsky provided the report layout. The research on which this report is based was conducted at the Disability Statistics Rehabilitation Research and Training Center.

SUGGESTED CITATION

Kennedy, J. and LaPlante, M.P. (1997). A profile of adults needing assistance with activities of daily living, 1991–1992. *Disability Statistics Report, (11)*. Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

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INTRODUCTION

Activities of daily living (ADLs)—basic self-care activities, such as bathing, eating, dressing, or getting around inside—have been widely used in clinical and research settings to assess disability in various populations (Spector, 1990). More recently, needing assistance with ADLs has become an important criterion for determining eligibility for public and private disability benefits.

Activity limitation indices, such as the Katz ADL scale (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963), have emerged as an integral part of aging and disability research, and numerous studies have identified clear and substantial linkages between ADL limitation and service utilization, health status, and socioeconomic factors. Limitations in basic self-maintenance have been found to be significantly related to mortality (Manton, 1988; Spector, Katz, Murphy, Fulton, 1987), morbidity (Guralnik, LaCroix, Branch, Kasl, & Wallace, 1991), and comorbidity (Verbrugge, Lepkowski, & Imanaka, 1989). ADL limitation has also been linked to socioeconomic status (Ficke, 1992), employment rates (McNeil, 1993), work disability (Ficke, 1992; LaPlante, 1988), living arrangements (Bishop, 1986), degree of family support (Frederiks, Visser, & Sturmans, 1990; Johansson, 1991; Stoller & Earl, 1983), and "caregiver burden" (Boaz & Muller, 1991; McFall & Miller, 1992). ADL limitation is related to health insurance coverage (Dunlop, Wells, & Wilensky, 1989; LaPlante, 1993), and it has proven to be a consistently robust predictor of service utilization in a number of areas, including

- hospital and acute care (Donaldson & Jagger, 1983; LaPlante, 1993; Spector et al., 1987),
- physician services (Wan & Odell, 1981),
- home health aide, nursing, and therapy services (Wolinsky et al., 1983; Evanshank, Rowe, Diehr, & Branch, 1987; Liu, McBride, & Coughlin, 1990; Mauser & Miller, 1994),
- paid personal assistance (Frederiks et al., 1990; Johansson, 1991; Stoller & Cutler, 1993; Liu, Manton, & Liu, 1985), and
- nursing-home care (Branch & Jette, 1982; McFall & Miller, 1992; Shapiro & Tate, 1985; Williams, Fries, Foley, Schneider, & Gavazzi, 1994).

As research continues to establish the linkage between limitations in ADLs and service utilization, policymakers have begun to employ these measures as indices of service need. ADL limitation is used both on a population basis—for example, to describe case mix for prospective payment purposes (Manton, Woodbury, Vertrees, & Stallard, 1993)—and on an individual basis, for program eligibility and service allocation. State personal assistance programs have also been influenced by ADL criteria in eligibility and allocation decisions (Kennedy, 1993), and various federal legislative initiatives in the past decade have built on these state criteria.

In 1990, the Omnibus Budget Reconciliation Act expanded the Medicaid Home and Community Based Services waiver, allowing states the option to redirect nursing home funds to home and community-based services for low-income persons who need assistance with two or more ADLs. Other Congressional proposals to extend personal assistance benefits have attempted to limit eligibility to those with the most severe disabilities only, using need for assistance with two or three of the five most basic ADLs (bathing, dressing, transferring, toileting, and eating) as a primary criterion. Future legislation will likely continue to base eligibility on assistance needs with multiple ADLs.

There are a number of reasons that ADL assistance criteria have legislative appeal. First of all, the fact that they reliably predict nursing-home admissions suggests that they are an appropriate targeting mechanism for programs intended to reduce institutionalization. They also perform an important triage function, by selecting a relatively small and, therefore, more fiscally manageable subset of the entire population with disabilities. Their face validity is also useful for building consensus to public policy—everyone eats, dresses, uses the toilet, bathes, and gets in and out of chairs and beds. Most people can readily appreciate the difficulties experienced by those needing help with these activities, and are therefore likely to agree that individuals in such circumstances merit some sort of public assistance.

As ADLs assume a more central role in national policy, the need for accurate national estimates across populations has become more pressing. This type of research is specifically focused on rates of ADL limitation, rather than their relationship to phenomena such as service utilization. Conceptually, ADLs are transformed from independent variables to dependent variables.

The published literature in this area is surprisingly limited, particularly given the magnitude and potential costs of the proposed federal benefits. While several recent descriptive analyses have assessed national activity limitation prevalence (Harpine, McNeil, & Lamas, 1990; LaPlante, 1991a; McNeil, 1993), published analyses of the number of persons who would be eligible for a federal personal assistant services (PAS) benefit under various ADL limitation criteria have focused only on the population aged 65 or older (Jackson, Burwell, Clark, & Harahan, 1992; Spector, 1991; Spillman & Kemper, 1992; Stone & Murtaugh, 1990).

This report uses data from the 1990 and 1991 samples of the Survey of Income and Program Participation (SIPP) to provide a profile of the noninstitutionalized adult population needing assistance with activities of daily living and to estimate the size of the population eligible for federal PAS benefits under different ADL, income, and age criteria. It also describes current sources of ADL assistance by recipient type.

HIGHLIGHTS

- An estimated 7.3 million adults living in the community are limited in their capacity to perform one or more of 5 basic ADLs (bathing, transferring, dressing, eating, toileting).
- Some 3.7 million adults, over half of the population limited in ADLs, require the assistance of another person in performing ADLs.
- Bathing is the most common ADL requiring assistance; next are dressing, transferring, toileting, and eating.
- Some 60.9 percent of those who need assistance with ADLs are aged 65 or older.
- Of those needing assistance with ADLs, 61.3 percent are women.
- An estimated 2.8 percent of blacks require ADL assistance, compared to 1.9 percent of whites and 1.3 percent of Hispanics.
- Only 0.5 percent of college graduates need ADL assistance, compared to 2.2 percent of non-graduates.
- People who need ADL assistance are almost twice as likely to have family incomes below the poverty line (20.2 percent) as people without ADL limitations (11.2 percent).
- Some 2.2 million adults need assistance with 2 or more ADLs. Of these, 1.3 million are 65 or older. Some 530,000 adults need assistance with 2 or more ADLs and have family incomes at or below the federal poverty level.
- An estimated 1.3 million adults need assistance with 3 or more ADLs. Of these, 900,000 are 65 or older. Some 300,000 adults need assistance with 3 or more ADLs and have family incomes at or below the federal poverty level.
- Among working-age adults needing assistance in ADLs, 18.3 percent of men and 10.7 percent of women are working full time, compared to 75.5 percent of men and 49.7 percent of women without ADL limitation.
- Among working-age adults needing ADL assistance, 13.7 percent of women and 7.8 percent of men report no income at all during the month prior to being interviewed.
- People who need ADL assistance are much more likely to receive public benefits: 37.6 percent of persons aged 15–64 who need ADL assistance are beneficiaries of one or more Social Security programs (i.e., SSDI and survivors benefits), compared to 3.8 percent of persons without ADL limitation.
- Over half of those who need ADL assistance (50.7 percent) rate their health as poor, compared to 2.7 percent of those without ADL limitations.
- Arthritis/rheumatism is the most common condition causing need for ADL assistance, followed by back/spine problems, heart trouble, and stroke.
- Almost half (47.2 percent) of those who need ADL assistance have needed this assistance for less than two years.
- Spouses, particularly wives, are the most common source of ADL assistance (38.0 percent), followed by daughters and other relatives.
- Type of family assistance varies by age and marital status. Older people are more likely to use paid providers.

METHODS

The Survey of Income and Program Participation

This analysis employs the 1990 and 1991 samples of the Survey of Income and Program Participation (SIPP), a household survey of the noninstitutional population of the United States administered by the Bureau of the Census. The survey's objective is to provide accurate and comprehensive cross-sectional and longitudinal data on personal and household income and program participation. The SIPP is widely viewed in the policy research community as the best available source of national data to model program eligibility and participation rates (Citro & Kalton, 1993; Doyle, 1992).

Kasprzyk (1988) describes the SIPP as a continuous rotating panel survey. It employs a complex multi-stage sampling strategy. A panel of approximately 15,000 U.S. households is selected each year, and each adult household member is interviewed eight times over the subsequent 28 months. Each round or wave of the eight interviews is broken into four subsamples called rotation groups, so interviews are spread out across the entire year. Because of this design, there are always two panels being interviewed in the field simultaneously. This feature allows data from different panels to be combined, increasing sample size and reducing sampling errors (Jabine, King, & Petroni, 1990).

This report uses aggregate data from the 1990 wave 6 and 1991 wave 3 SIPP panels, administered simultaneously during the period between October 1991 and January 1992. The combined dataset holds 90,345 individual records, 69,403 of which are for adults age 15 or older. The weighted population counts are comparable to published Decennial Census and Current Population Survey data (McNeil, 1993) and to the National Health Interview Survey (LaPlante, 1993).

During the first wave, the interviewer establishes a control card for each household, which contains basic demographic information for each person residing at the address, including age, gender, race, marital status, and education level. In subsequent waves, the interview begins by verifying the data on the control cards and noting any changes (e.g., marriage or divorce of a household member).

Each adult is then administered a core survey questionnaire, containing those questions asked in every wave. Respondents are also given one or more topical modules, the contents of which vary from wave to wave. These sets of questions are intended to meet the special programming needs of other federal agencies (involving child support, pension coverage, housing costs, or energy usage, for example), which may change from year to year. This analysis uses disability variables from the Topical Module on Functional Limitation and Disability. Appendix A describes how the SIPP defines these variables.

Estimation Procedures

The SIPP uses a complex multi-stage weighting procedure, employing population estimates derived from the Decennial Census and the monthly Current Population Survey (CPS). Each household is first assigned a base weight, which is equivalent to the inverse of that household's probability of selection. If there were no problems with undercoverage or non-response, this weight would provide unbiased population estimates.

Each interviewed household is then assigned a non-interview adjustment factor to the base weight. Adjustment cells are based on the following variables: census region (Northeast, Midwest, South, West), residence (metropolitan, suburban, rural), tenure (homeowner, renter), race (black, non-black), and household size (1, 2, 3, 4 , or greater than 4 persons).

A first-stage ratio estimation factor is intended to reduce the stratification sampling error—in other words, to account for SIPP sample areas that do not have the same population distribution as the strata they are selected from—and is applied to households in non-self-representing primary sampling units (PSUs). Estimation cells are based on census region, residence, and race.

A second-stage adjustment factor, assigned to all interviewed individuals, is intended to partially correct for undercoverage of persons according to age, race, Hispanic origin, and gender. Independent estimates within cells are based on updated population counts from the Decennial Census. CPS estimates of the number of persons within households by race (black versus non-black), gender, marital status, and family status are also used as controls.

Missing Data

Imputation is used in the SIPP to correct for item non-response, person non-response, and values that fail consistency edits. The Census

Bureau uses a "hot deck" method of imputation, in which values for missing items are assigned by identifying responses from other individuals with similar characteristics. Basic demographic variables, such as age, gender, race, income, and education, are used for the imputation process, depending on the imputed item (Singh & Petroni, 1988). This methods-driven approach may introduce significant bias to some population estimates (Doyle & Dalrymple, 1987).

The SIPP data files have indicator variables for each imputed variable, allowing users to assess the prevalence of missing data and the characteristics of the imputed population. For the main criterion variable in this analysis, limitation in ADLs, the overall imputation rate is 9.8 percent. The rate is higher among younger persons, males, and minorities, consistent with previous analyses of the SIPP (McNeil, 1993). Both imputation and weighting are employed in this analysis to optimize the accuracy of the estimates.

Reliability of Estimates

All population estimates of standard errors directly account for sampling structure using the SUDAAN software package. Because of their instability, very low prevalence estimates (estimated population less than 30,000) are indicated with dashes on all summary tables. Following the protocol established by the National Center on Health Statistics (NCHS), reliability of estimates is assessed by calculating the relative standard error (RSE) for each variable (x), with estimates having a RSE over 30 percent deemed statistically unreliable.

Background: The Development and Structure of Activity Limitation Scales

Measures of basic activity limitation typically consist of an inventory of self-maintenance tasks. Individuals are assessed in their ability to perform these tasks. One of the first and most influential measures of sociobiological function was the Index of Independence in Activities of Daily Living, developed by Sidney Katz and his colleagues in a study of clinical outcomes in hip fracture patients (Katz et al., 1963). The Katz ADL scale is a clinical measure of performance, based on direct observation or discussion with the client or caregiver. "Dependence" (receiving supervision, direction, or active personal assistance from another person) is assessed in each of the following areas: bathing, dressing, toileting, transferring, continence, and feeding. The scaling assumes a hierarchy of capacity, in that a person limited in one of the latter (more basic) activities will presumably also be limited in all of the former (less basic) ones.

Katz and Akpom (1976) hypothesize a reverse developmental process, whereby ability to perform an ADL is lost in the opposite order it is acquired. Specifically, children first learn to control their ability to eat and eliminate, whereas only later do they learn to bathe or dress themselves. Katz and Akpom pointed out that persons recovering from a stroke go through the same learning (or relearning) process. Similarly, those with progressive chronic impairments lose their capacity to perform ADLs in reverse chronological order of acquisition.

There is thus a longitudinal and cross-sectional dimension to the hierarchical pattern described by Katz and Akpom. In a population cross-section, one would expect a higher prevalence of less basic ADL limitation (for example, bathing) and a lower prevalence of more basic ADL limitations (for example, feeding). One would also expect that persons limited in more basic ADLs would also be limited in less basic ADLs. In a longitudinal sample, one would expect transitions in ADL status to conform to this hierarchy as well. People experiencing a decline in function should acquire new limitations in more basic ADLs, whereas people improving in function should gain in capacity to perform more basic ADLs.

Other researchers have developed and refined numerous gradients of activity limitation, adjusting the content and range of activities assessed to meet their various research objectives and conform to the population characteristics of their subjects. A review of published functional disability indices identified over forty different scales assessing self-care and mobility (Feinstein, Josephy, & Wells, 1986).

Spector (1990) distinguishes between performance measures like the Katz Scale and capacity measures like the Barthel Index, a list of 15 self-care and mobility items. The performance questions take the basic form, "Does person X perform task Z?," while the capacity questions take the form, "Can person X perform Z?" The two are obviously closely related, but performance measures are directly observed, while capacity measures are inferred from responses by subjects (or their surrogates) to hypothetical questions.

Spector argues that performance measures are more concrete, but they can be affected by

motivational and environmental factors. Capacity measures, on the other hand, are generally set in hypothetical terms and therefore subject to misinterpretation. For the study of large populations, capacity measures have a number of practical advantages. They can be included in surveys and administered by non-clinical staff via interviews or mailed questionnaires, while performance measures require direct observation of subjects by clinically trained evaluators (Shinar et al., 1987). Some sort of inventory of functional capacity is now a common feature of most large health surveys, including the SIPP.

FINDINGS

ADL Prevalence Rates

Table A provides data distinguishing the population needing help with ADLs from those who report difficulty with ADLs but do not need assistance. The two categories can be combined to get an estimate of the total prevalence of a given limitation. For example, 5.2 million people, or 2.7 percent of the total adult population, are limited in transferring, the ability to get in and out of a bed or chair. The ADL estimates for adults aged 65 or older are comparable to those of other national surveys like the NHIS and NMES (see Appendix B).

Transferring is the most common source of limitation among the five ADLs. However, only 2 million of those limited in transferring need the assistance of another person in performing this activity. The majority of respondents who report limitations in bathing, dressing, and toileting also report need for assistance with these activities.

Limitations in bathing are the most common source of need for ADL assistance—2.7 million adults say they need help in taking a bath or shower. Dressing is the second most common ADL in which assistance is needed, followed closely by transferring. Toileting is a less common assistance need, and eating is the least common source of limitation and of need for assistance—fewer than 500,000 people need help with this activity.

Overall, 7.3 million people 15 years and older have some difficulty with one or more ADLs. Half of those adults (3.7 million) reporting an ADL limitation also report a need for assistance. About 1.5 million of these need help with only one ADL, and 1.4 million need help with three or more ADLs.

Duration of ADL Assistance

Table 1 shows retrospective estimates of duration for people who need help with ADLs at the time of the interview. Almost half (47.2 percent) of those who report needing help say that they have been in this state for less than two years, and 20.3 percent of those say they have needed help for less than one year. On the other hand, 31.0 percent have needed help for five years or more.

There are no clear differences in duration of ADL assistance need by gender, race or ethnicity. There is also no clear relationship between duration and severity (defined by the number of ADLs for which assistance is needed), except at the high end of the distribution: persons limited in a higher number of ADLs are more likely to have needed assistance for a longer period of time. The younger age groups are likely to report longer duration of ADL assistance.

Population Characteristics of ADL-limited Groups

The prevalence rate of limitations in ADLs and need for assistance with ADLs varies by age, gender, race, ethnicity, and marital status (Table 2). Age is very closely tied to limitations in ADLs, in both relative and absolute terms. Although only 15.7 percent of the total adult noninstitutionalized population is over age 65, this subgroup accounts for 60.9 percent of all adults who need assistance with ADLs. A similar pattern holds for people who are only limited in ADLs—over half (50.8 percent) are aged 65 or over. The mean age for those not limited in ADLs is only 41.8, compared to 62.2 for people limited in ADLs but not needing assistance and 65.1 for people needing ADL assistance. These age differences become even more pronounced when one examines the relative prevalence rates. Only 0.3 percent of adults under age 25 need help with ADLs, but these rates rise rapidly with age, to 22.9 percent of adults age 85 or older.

It is well-established that age is also highly correlated with gender, marital status, and education. Mean age is therefore also reported in Table 2 as a possible explanation for the variation in rates of ADL limitation for these categories. For example, the widowed category, with a mean age of 70.3, has rates of ADL assistance need that are almost 9 times higher than among adults who have

Table A. Personal Assistance Needs and ADL Limitations Among People Aged 15 and Over, 1991–92.

ADL Limitation	Population (1000s)	SE	Proportion of Population (%)	SE
Transferring				
Difficulty	3,221	130	1.7	0.06
Needs help	2,022	79	1.0	0.04
Bathing				
Difficulty	1,759	80	0.9	0.04
Needs help	2,710	98	1.4	0.05
Dressing				
Difficulty	1,163	80	0.6	0.04
Needs help	2,057	75	1.1	0.04
Eating				
Difficulty	587	44	0.3	0.02
Needs help	487	42	0.3	0.02
Toileting				
Difficulty	921	68	0.5	0.04
Needs help	1,154	64	0.6	0.03
No ADL limitation	187,588	1,625	96.3	0.10
Difficulty only with 1 or more ADLs	3,597	136	1.9	0.07
Need assistance with 1 ADL	1,523	86	0.8	0.04
Need assistance with 2 ADLs	765	50	0.4	0.03
Need assistance with 3 ADLs	488	45	0.3	0.02
Need assistance with 4 ADLs	585	46	0.3	0.02
Need assistance with 5 ADLs	315	34	0.2	0.02

Source: 1990 and 1991 SIPP Topical Module on Functional Limitation and Disability.

never married (7.9 percent versus 0.9 percent) but the latter group has a mean age of only 26.6.

Women account for 61.5 percent of noninstitutionalized adults limited in ADLs. About 1.5 percent of adult males need help with ADLs, while 2.2 percent of adult females need help. These gender differences are due in part to differences in longevity. As one indication, the mean age for adult women in the sample is 43.5, compared to 41.6 for men.

Rates of limitation are highest for blacks and lowest for the "non-Hispanic other" category. Some 2.8 percent of blacks need assistance with one or more ADLs. Among whites, 1.9 percent need assistance, but only 0.8 percent of the "other" group require assistance. Some, but not all, of this variation may be due to differences in mean age within the groups; population groups with high immigration and birth rates, for example, tend to be younger and consequently experience less disability. The Hispanic and other categories have mean ages of 37.6 and 38.4, respectively, compared to a mean age of 43.5 for whites. Yet blacks have a lower mean age (39.4) than whites, suggesting that race and ethnicity do have an effect on rates of limitation independent of age.

Persons with lower levels of schooling have higher rates of ADL limitation. Again, part of this

difference is due to an age effect—those with less than a high school education have an average age of 45.6, compared to 43.2 for high school graduates and 43.6 for college graduates. Yet despite similar mean ages, high school graduates have rates of ADL assistance need that are almost four times higher than those of college graduates (1.9 percent versus 0.5 percent), suggesting a relationship independent of age.

Workforce and Program Participation Rates

Table 3 contrasts median personal incomes and rates of labor force participation among working-age adults in the three limitation categories. These are further broken down by gender to account for general disparities in employment rates between men and women.

A significant proportion of the population report receiving no income at all during the reference month in question, and gender and ADL limitation both affect the likelihood of falling into this category. Women aged 18–64 who need assistance with ADLs are twice as likely as men without ADL limitations to have no income (13.7 percent versus 6.2 percent).

Median incomes, calculated only among respondents with non-zero income, are much lower for those with ADL limitations. Annual median income for men without ADL limitations is $21,954, compared to $9,585 for men who need assistance with ADLs. Similarly, women without ADL limitations have a median income of $11,990, but women who need assistance with ADLs have a median income of only $5,200.

There are also marked differences in rates of employment. While 49.7 percent of all women and 75.5 percent of all men without ADL limitations are working full time, only 10.7 percent of women and 18.3 percent of men who need ADL assistance are working full time. Adults who are limited in ADLs but do not need assistance also have much lower rates of labor force participation than those not limited. Both of the limited groups also have lower rates of part-time employment than the non-limited group.

Much, but not all, of the disparity in rates of workforce participation is attributed to disability. Two-thirds of working-age men (66.0 percent) and women (65.5 percent) who need help with one or more ADLs say that they are unable to work "because of a physical or mental condition," compared to 3.5 percent of men and 4.0 percent of women without ADL limitations.

Family income tends to be much lower for people limited in ADLs than for those who are not (Table 4). The median annual family income of people who need help with one or more ADLs is $19,272, compared to $32,857 for people without ADL limitations. Median family incomes are even lower for people who are limited in ADLs but do not need assistance—$15,686 per year—presumably due to lower levels of transfer income.

This pattern is also apparent in the annual family income levels. People who are limited in ADLs but do not need assistance, are most likely to have low family incomes—48.5 percent receive less than $15,000 per year and only 9.0 percent receive over $50,000 per year. People who need help with ADLs are also more likely to have low family incomes—38.4 percent receive less than $15,000, and 10.6 percent receive over $50,000.

Table 5 describes rates of program participation among noninstitutionalized adults aged 15 to 64 and aged 65 or older. These two groups are separated to distinguish differences due to disability from differences due to age-based eligibility criteria. Not surprisingly, participation rates for Social Security and Medicare are high overall among persons aged 65 or older, and consequently there is little variation by disability status.

In the younger age group, however, there are marked differences in program participation rates. While 3.8 percent of working-age adults without ADL limitations receive Social Security payments (SSDI or Survivor's Benefits), 37.6 percent of working-age adults who need ADL assistance receive payments. Only 1.2 percent of the non-limited group is covered by Medicare, while 28.1 percent of those needing ADL assistance are covered. The limited groups have extremely low (and statistically unstable) rates of unemployment and general assistance (GA) recipiency, but relatively high rates of workers' compensation recipiency (4.9 percent for those needing help with ADLs and 5.6 percent for those who are limited in one or more ADLs but do not need assistance, compared to less than 0.4 percent of non-limited adults). The rate of recipiency for Aid to Families with Dependent Children (AFDC) is almost twice as high (4.0 percent) for those needing assistance with ADLs as for those not limited in ADLs (2.1 percent).

Medicaid and Supplemental Security Income (SSI) participation rates in both age groups are much higher for those limited in or needing assistance with ADLs. About 32.4 percent of adults

under 65 and 19.9 percent of those over 65 who need help with ADLs are covered by Medicaid, compared to 5.6 percent of non-limited adults under age 65 and 6.5 percent of adults over age 65. Only 1.3 percent of non-limited adults under age 65 and 4.7 percent of non-limited adults over 65 receive SSI, while SSI recipiency among adults needing assistance with ADLs is 21.0 percent for those under age 65 and 14.1 percent for those over 65.

Health Status and Conditions

In Table B, self-reported health status is broken down by limitation status. ADL limitation and health status are closely linked. While 61.7 percent of people without ADL limitation say they are in excellent or very good health, only 5.4 percent of people with ADL limitations report this level of health. Indeed, over half of those who needed help with ADLs (50.7 percent) describe their health as poor.

Table C shows health conditions causing ADL limitation. The SIPP condition codes are relatively constrained (and occasionally ambiguous), and a number of response categories had to be dropped due to low prevalence and high relative standard error. The most common condition reported as causing ADL limitation is arthritis and rheumatism, followed by back or spine problems, "other (nonspecified) condition," and heart trouble. Strokes are a major reason for needing ADL assistance, but not for ADL limitation without need for assistance. These findings are roughly comparable to the more extensive work by LaPlante (1991b, 1996).

Senility/dementia/Alzheimer's, mental retardation, and mental or emotional disorders are ranked respectively as the 12th, 13th, and 16th major reasons for needing ADL assistance. A separate set of probes asked about various psychiatric and cognitive conditions, without linking them to ADL status (see Table D). These elicited higher rates among the population needing assistance with ADLs. For example, only 125,000 people need ADL assistance because of senility, dementia or Alzheimer's, but 327,000 people who need ADL assistance also report this condition. This suggests a fairly high rate of comorbidity.

Program Eligibility Estimates

As mentioned in the Introduction, eligibility under various proposed and existing benefit programs depends on the extent of ADL limitation. Figure 1 contrasts the number of people eligible at all ADL levels under different age and income criteria. If eligibility is based solely on need for assistance with at least 2 of 5 ADLs, approximately 2.2 million people would be eligible for services. Raising the limitation level to 3 of 5 ADLs reduces the eligible population by 36 percent, to 1.4 million.

If eligibility is limited to older people (over age 64) who need assistance with 2 of 5 ADLs, approximately 1.3 million people would be eligible for services. Raising the limitation level to 3 or more ADLs would drop the population to 900,000.

If eligibility is linked to low family income as well as ADLs, the size of the eligible population would be dramatically reduced. Requiring family incomes to be at or below the poverty level, in addition to needing assistance with 2 of 5 ADLs, would reduce the eligible population to approximately 530,000. Only 305,000 people have incomes below poverty level and need assistance with 3 or more ADLs.

Table B. ADL Status by Self-assessed Health Status, 1991–92.

	Total				Not Limited				Limited Only				Need Help			
Health Status	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE
Excellent	57,063	676	29.3	0.3	56,961	680	30.4	0.3	45	11	1.3	0.3	57	11	1.6	0.3
Very good	59,140	814	30.4	0.3	58,832	809	31.4	0.3	166	28	4.6	0.8	142	19	3.9	0.5
Good	50,198	633	25.8	0.2	49,091	630	26.2	0.3	612	46	17.0	1.2	495	36	13.5	0.9
Fair	20,166	296	10.4	0.1	17,616	277	9.4	0.1	1,431	89	39.8	1.8	1,119	61	30.4	1.2
Poor	8,295	215	4.3	0.1	5,088	170	2.7	0.1	1,343	79	37.3	1.6	1,864	81	50.7	1.5

Source: 1990 and 1991 SIPP Topical Module on Functional Limitation and Disability.

Table C. Medical Conditions Causing Difficulty or Need for Assistance in ADLs Among Persons Aged 15 or Older, 1991–92.

Conditions	Limited Only		Need Help	
	Population (1000s)	SE	Population (1000s)	SE
Arthritis or rheumatism	975	67	627	45
Back or spine problems	784	58	432	41
Other (not specified)	374	39	420	43
Heart trouble (e.g. heart attack, hardening of the arteries)	306	31	309	26
Stroke	75	16	305	32
Lung or respiratory trouble	176	27	209	31
Paralysis of any kind	82	16	152	27
Stiffness or deformity of foot, leg, arm, or hand	143	24	106	17
Cancer	93	22	113	20
Diabetes	86	13	106	23
Broken bone/fracture	71	19	111	18
Senility/dementia/Alzheimer's disease	32 *	10	125	17
Mental retardation	22 *	10	95	16
Head or spinal cord injury	52	14	93	19
Blindness or vision problems	50	11	78	17
Mental or emotional disorder	52 *	18	62	15
High blood pressure (hypertension)	54	13	49	13
Missing legs, feet, arms, hands, or fingers	32 *	10	49	12
Alcohol or drug problem or disorder	28	8	40	12
Kidney stones or chronic kidney trouble	11 *	5	39	10
Cerebral palsy	11 *	5	35 *	11

Source: 1990 and 1991 SIPP Topical Module on Functional Limitation and Disability.

Note: Conditions not included due to low incidence and/or high relative standard error: AIDS or AIDS related condition, deafness or serious trouble hearing, epilepsy, hernia or rupture, learning disability, speech disorder, stomach trouble, thyroid trouble or goiter, tumor, cyst, or growth.

* Estimate has low statistical reliability (relative standard error > 30%).

Table D. Prevalence of Difficulty or Need for Assistance in ADLs Among Persons Aged 15 or Older with Cognitive Limitations, 1991–92.

Special Cognitive Probes	Limited Only		Need Help	
	Population (1000s)	SE	Population (1000s)	SE
Mental or emotional condition	231	30	240	27
Learning disability (e.g., dyslexia)	99	22	121	19
Senility/dementia/Alzheimer's disease	51	13	327	37
Mental retardation	34 *	11	145	19
Developmental disability (e.g., cerebral palsy or autism)	30 *	14	90	17

Source: 1990 and 1991 SIPP Topical Module on Functional Limitation and Disability.

* Estimate has low statistical reliability (relative standard error > 30%).

Less stringent income criteria yield larger eligible populations. Among those needing help with 3 or more ADLs, 402,000 have family incomes at or below 125 percent of the poverty level, 521,000 have family incomes at or below 150 percent of the poverty level, and 733,000 have family incomes at or below 200 percent of the poverty level. .

A less hypothetical approach to program eligibility rates is also possible with the SIPP, using actual program participation data to determine the portion of current beneficiaries who need ADL assistance. Table E shows the number of Medicare, Medicaid, and SSI program participants who would be eligible for an "add-on" personal assistance benefit based on their ADL status, contrasting those figures with the general population estimates used to generate Figure 1.

There are some noticeable, though explainable, differences between the rates under the hypothetical Medicaid and Medicare scenarios and the estimates of those who need assistance among current Medicaid and Medicare program beneficiaries. The higher number of current Medicare recipients needing ADL assistance includes recipients under age 65. The number of current Medicaid recipients who need help with ADLs is slightly higher than the number of people with family incomes below the federal poverty level. This may reflect the fact that some states employ slightly more generous income-eligibility criteria than the federal poverty level to determine SSI eligibility.

Sources of ADL Assistance

Table 6 shows the sociodemographic characteristics of recipients by type of primary source of ADL assistance. Table 7 shows these characteristics by secondary source of assistance. Only 41.2 percent of persons who report needing ADL assistance identified a secondary assistance provider.

The most consistent finding is the reliance on various family members to provide ADL assistance. Spouses are the most common primary providers (38.0 percent), followed by daughters (19.4 percent) and other relatives (11.6 percent). Only 9.2 percent of the population needing ADL assistance use paid providers as their primary source of assistance. Sons are primary providers for 8.0 percent of the population. Secondary sources of assistance exhibit a slightly different pattern, but family assistance is still dominant. Other relatives constitute the main source of secondary assistance (24.5 percent), followed by daughters (19.4 percent), paid help (18.1 percent), and sons (15.7 percent).

As expected, the type of family provider depends on the circumstances of the recipient. Unmarried adults (a comparatively young population) often rely on their parents (36.3 percent) or other relatives (27.0 percent) for their primary assistance, and a significant proportion use paid providers (11.3 percent). Married persons almost invariably rely on their spouses (75.8 percent). Persons who are widowed, separated, or divorced are much more likely to have their daughters, sons, and other relatives as primary assistants.

Parents are the only significant source of ADL help reported for the small number of young adults (aged 15–24) needing assistance (62.1 percent). Older persons with disabilities are most often assisted by daughters. Looking across age groups, the use of spouses for assistance peaks at 50.5 percent for adults aged 65–74, but declines steeply thereafter. Only 13.1 percent of adults aged 85 or older rely primarily on a spouse, while 20.0 percent use paid providers.

Some interesting patterns emerge with regard to the gender of the assistance recipient and the gender of the family provider. Fully 54.9 percent of all men receive primary ADL assistance from their wives, while only half as many women (27.4 percent) receive primary assistance from their husbands. This difference can be attributed in part to differences in longevity, but may also be seen as evidence of the gender role disparities identified by analysts such as Fraser (1989) and England, Keigher, Miller, & Linsk (1991).

In terms of primary assistance, sons and daughters help their fathers at roughly the same rate (7.0 percent versus 7.9 percent), while daughters are three times more likely than sons to help their mothers (26.6 percent versus 8.7 percent). This, too, is presumably due in large part to longevity differences (both the mothers and daughters are likely to be older than their male counterparts), but may also suggest a preference for same-sex assistance for child providers and recipients (Lee, Dwyer, & Coward, 1993).

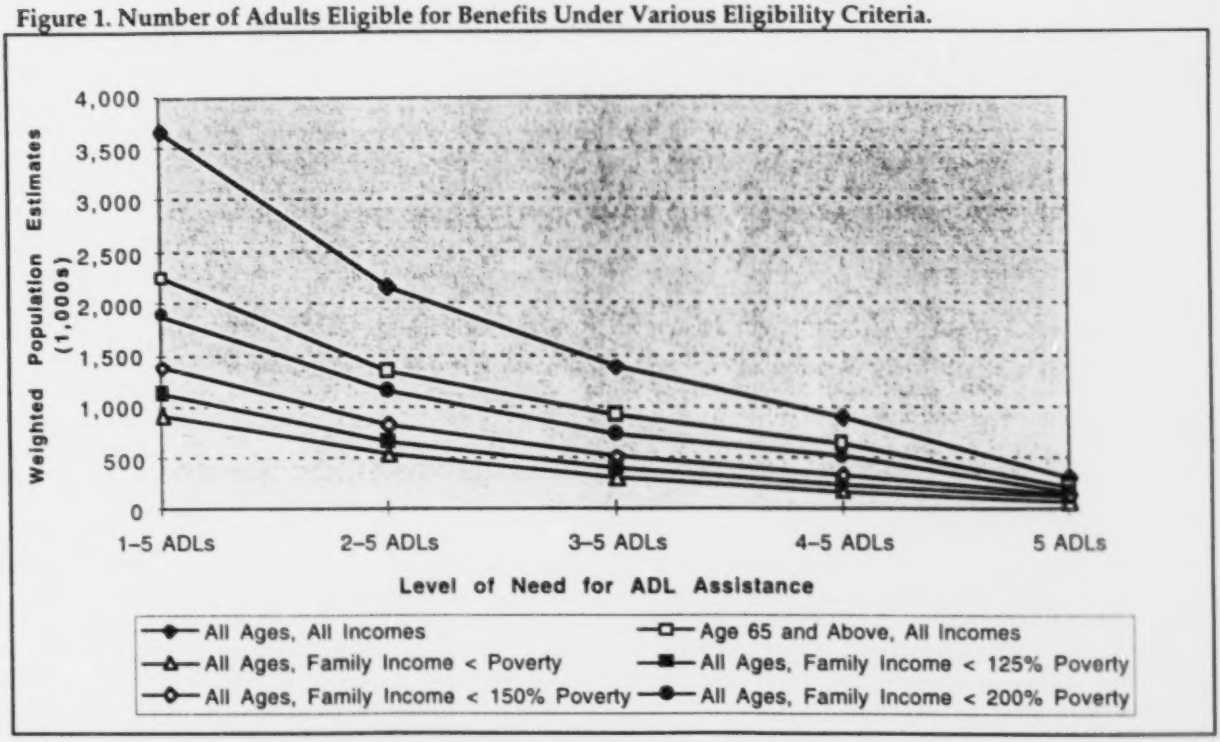
Combining data from Table 6 and Table 7, about 600,000 people report that they used a paid provider as either a primary or secondary source of ADL assistance. Separate probes about payment suggest that over 20 percent of this group pay out-of-pocket for at least some of this assistance. About 200,000 people who need ADL assistance report some out-of-pocket assistance expenses in the previous month, and the average monthly expenditure is about $380.

Table E. Eligibility of People Aged 15 and Over Under Different ADL, Age, and Income Criteria, and ADL Status of Current Medicare and Medicaid Beneficiaries.

Policy Scenario	Needs Help with 2 or more ADLs		Needs Help with 3 or more ADLs	
	Population (1000s)	% of population	Population (1000s)	% of population
Clinton/Pepper (ADLs only)	2,153	1.1	1,387	0.7
Medicare (ADLs + Age 65 or older)	1,334	0.7	901	0.5
Current Medicare Recipients	1,590	0.8	1,059	0.5
Medicaid (ADLs + poverty)				
< poverty level	531	0.3	305	0.2
< 125% poverty level	663	0.3	402	0.2
< 150% poverty level	825	0.4	521	0.3
< 200% poverty level	1,160	0.6	733	0.4
Current Medicaid Recipients	571	0.3	347	0.2

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

Figure 1. Number of Adults Eligible for Benefits Under Various Eligibility Criteria.



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CONCLUSIONS

Program Eligibility

1. Roughly 1.4 to 2.2 million adults would be eligible for a federal personal assistance benefit under basic ADL criteria.

The ADL assistance criteria identify a proportionally small, but numerically substantial group of adults living in the community who need personal assistance with the most basic tasks of self-maintenance. If a federal benefit employed only a 2-of-5 ADL assistance criterion for eligibility determination, 2.2 million adults (1.1 percent of the total adult noninstitutionalized population) would be potentially eligible for benefits. Raising this criterion to 3 of 5 ADLs would drop the population to 1.4 million (0.7 percent).

Yet there is little reason to expect that all those reporting need for ADL assistance would in fact apply for public benefits. Answering survey items involves a very different set of behaviors than applying for a personal assistance benefit. The individual decision to apply for such benefits would be based on consumer preferences and the nature of those benefits, as well as the eligibility criteria. Specifically, the availability, accessibility, and desirability of public services would be weighed in each case against the private alternatives.

A different concern is that ADL criteria, at least as specified in the SIPP and similar surveys, may not adequately identify the numerically and politically significant populations with cognitive or psychiatric disabilities who could benefit from appropriate personal assistance services (Kane, Saslow, & Brundage, 1991; Kasper, 1990; Spector, 1991). While each of the Congressional proposals identified earlier includes some sort of provision of standby ADL assistance, the SIPP items do not specify this type of assistance need. This may lead to bias in the disabilities identified, and could also lead to undercounting of total need for assistance (Stone & Murtaugh, 1990).

From a public cost-containment perspective, there are advantages to using more restrictive ADL criteria. But setting unduly restrictive disability criteria risks undercoverage of a population with potentially substantial service needs (Somerville, Silver, & Patrick, 1983). Kennedy (1994) raised this concern in his critique of the Clinton plan, observing that non-eligible persons with disabilities may be at greater risk of secondary disability, declining health status, and eventual institutionalization.

The real policy issue is not the precise ADL threshold used, but whether the eligibility criteria accurately and reliably identify the service needs of the population with severe disabilities. Spector (1991) points out that rigid adherence to ADL thresholds "may result in great inequities, as persons just below the cutoff receive no care, whereas those just above may receive large amounts of care. . . . alternatively, a broad look at the amount of care needed for a particular level of need may result in a benefit structure with a more continuous relationship between benefits and need."

2. Means-testing has a very large effect on total program eligibility counts.

The additional requirement of strict family income means-testing shrinks the size of the eligible population precipitously. Although disability is associated with poverty, only one-quarter of the population needing help with 2 of 5 or 3 of 5 ADLs also has family income less than or equal to the 1991 federal poverty level. About 347,000 Medicaid recipients need help with 3 or more ADLs. It is important to note, however, that modest adjustments that raise the family income criteria above the poverty line significantly increase the proportion of the population eligible for benefits (doubling the income threshold, for example, nearly doubles the size of the eligible population), suggesting that a large portion of the population needing ADL assistance is "near poor."

3. Younger adults with disabilities constitute over one-third of the adult population needing ADL assistance.

Young adults make up a significant portion of the adult population needing ADL assistance—35 percent of adults who need assistance with 3 or more ADLs are under age 65. The younger population with significant ADL limitations may have distinct support service needs, particularly related to work and child care (DeJong, Batavia, & Griss, 1989). This study shows that 80 percent of adults under age 65 with ADL assistance needs are not in the workforce, compared to 25 percent of non-limited adults. Advocates maintain that one of the main reasons for this disparity is inadequate or

absent personal assistance services in the home and on the job (Nosek & Howland, 1993).

If the lack of personal assistance constitutes a serious impediment to workforce participation, then there may be good reason to establish an independent system of support services, specifically for young people with disabilities who are currently employed or seeking employment. This is a very different policy goal than the prevention of institutionalization, and it may require a separate type of program. The Health Security Act, for example, has a separate provision regarding tax credits for PAS users who are working or seeking work (Kennedy, 1994). These estimates suggest that the size of the younger population needing substantial ADL assistance is relatively small, and presumably would be further reduced if benefits are limited to persons with long-term limitations.

4. A significant proportion of ADL limitations appear to be short-term.

About 20 percent of the population reporting ADL assistance needs have needed assistance for less than one year. While some may continue to require assistance for a longer period, others will not. More generally, the substantial dynamism in self-reported ADL status has important implications for disability programming. Within the 1990 SIPP panel, almost half of those who report needing assistance with one or more ADLs do not report needing assistance a year later. While this instability of ADL status may be bothersome to researchers, it can be comforting to policymakers. Liu, Manton and Marzetta (1990) observe mortality and functional improvement within the population needing ADL assistance, both of which substantially reduce the likelihood of institutionalization.

It is clear that short-term activity limitation does not warrant the provision of long-term support services. Policymakers, therefore, must consider duration thresholds for program eligibility, as well as ADL, age, and income thresholds. Documentation of duration of ADL limits is, however, more of a challenge for program administrators than documenting departure from the workforce due to disability (the main criteria for programs like workers' compensation). How "long-term" ADL assistance is defined will have a substantial effect on the size of the eligible population.

5. Most people with ADL assistance needs get help from family members.

The SIPP data verify that family members provide the bulk of ADL assistance and that the type of family assistance varies by age and marital status. This fact has several implications for a federal benefit: First, any direct payment or special tax treatment of family providers will have a substantial effect on program participation rates and total program costs. If, on the other hand, program eligibility is made contingent on the absence of family support, then serious questions of equity and adequacy arise (England et al., 1991; Estes, 1991).

There is concern among policymakers that the introduction of new non-family sources of assistance will encourage substitution of "formal" support for "informal" support, thus raising public costs with no net gain in level of support for the individual with a disability (although it may reduce "caregiver burden"), but economic analyses of home- and community-based services to date show little evidence of substitution, leading most researchers to conclude that they are conceptually distinct service domains (Christianson, 1988; Edelman & Hughes, 1990; Greene, 1983; Hanley, Wiener, & Harris, 1991; Moscovice, Davidson, & McCaffrey, 1988). Leutz (1986) concludes that "both the public sector's fear of 'welfare cheats' and the private sector's obsession with 'moral hazard' are greatly exaggerated . . . . if we could support families instead of spending so much energy worrying that we will replace them, long-term care policy would be better off."

Whether the reliance on family for ADL assistance represents a real consumer choice (Brecher & Knickman, 1985) or simply a lack of other alternatives (Nosek, 1993) depends on the individual circumstances and preferences of the recipient. But the current "system" of informal support often entails substantial economic, social, and psychological costs to the assistance recipient and his or her family. Any effective policy intervention should recognize and attempt to mediate these costs. In this context, one would expect some substitution of formal for informal support with the introduction of new services.

6. ADL assistance requirements are useful in delimiting categories of need.

ADLs offer an adequate, though not ideal, way for governments to delimit categories of need.

Programs targeted to "the aged and disabled" often assume stability in the size and composition of the target population. But disability status, unlike chronological age, is sensitive to changes in the social and economic environment. While assessing capacity to perform ADLs is less contextual than assessing capacity to work, there is some potential for deception or confusion on the part of disabled individuals or their agents—a perennial source of alarm for critics of the welfare state.

Nonetheless, in the absence of a compelling alternative, ADLs remain the most accessible and readily applicable measure of disability for descriptive policy purposes. They effectively reduce the size of the population with disabilities to a small and fiscally manageable level. They have been strongly and repeatedly linked to service utilization, and are widely accepted by researchers and program administrators. They have compelling face validity, using universally required self-maintenance tasks which are readily understood by the public.

Research criticisms of ADL status (e.g., Zola, 1993) are similar to those of socioeconomic status (e.g., Nickens, 1995; Schulman, Rubenstein, Chelsey, Eisenburg, 1995), namely that they are deceptively simple indicators of a complex array of interrelated social and individual factors. While the correlation of ADL status, socioeconomic status, and health status is well established, the causal explanations put forward for this relationship have so far been limited (Maddox & Clark, 1992).

ADLs appear at first glance to be value-free and constituency-neutral, but demographic analyses indicate that they are correlated with various socioeconomic markers of disadvantage, such as race, education, income, program participation, and workforce participation. Even if eligibility for a public benefit is based exclusively on need for assistance with ADLs, it will tend to serve an older subpopulation that has a higher proportion of women, African Americans, and persons with lower levels of income, education, and workforce participation. Means testing and age requirements accentuate this targeting of benefits.

Old age has historically been the basis of most significant social insurance programming in the United States, most notably Social Security and Medicare, but this is now changing (Hudson, 1994). Torres-Gil and Puccinelli (1994) observe, "We may be in the midst of a transition from the legacy of a modern aging period (1930–1990), when there was widespread support for age-based criteria, to a new aging period in which old-age alone may not be sufficient grounds for certain public benefits." Functional eligibility criteria, such as ADL assistance, are likely to become more widespread as the population ages.

Poverty is at least as salient a dimension of need as ADL assistance, and so there may be good political and economic reasons for integrating these criteria. There is a powerful normative argument for targeting limited public resources to persons who meet multiple criteria of need; for example, a paraplegic, single mother in East Los Angeles may not need as much ADL assistance as a wealthy, quadriplegic widow in Beverly Hills, but she presumably has more need for publicly subsidized assistance. This observation does not mean, however, that the strict federal definition of poverty is an appropriate cut-off point for benefit eligibility.

In summary, ADLs appear to be a valid and appropriate way of defining categories of need. The main policy risk in using these measures is that they may come to define the scope of service need. The constant framing of need in terms of ADLs is leading many analysts and program administrators to define and limit the services offered to that most basic level of need. It is the reductionism implicit in functional assessment that analysts like Batavia (1991) find "demeaning and dehumanizing."

The truncated and inflexible service package available in most state personal assistance programs is a frequent source of consumer complaints (Kennedy, 1993). Services are typically limited to a core of basic personal and household tasks, and provided only in the home. Most programs do not provide assistance with a range of other critical tasks, such as assistance with child care, heavy cleaning and maintenance, paramedical services, respite and emergency services, non-medical escort, and transportation. Such programs are therefore practically useless to a large portion of the population technically eligible for benefits. The policy challenge is to utilize ADL measures to assist in eligibility determination while not coupling benefits and services too tightly around them.

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Table 1. Duration of need for ADL assistance, by gender, age, race and ethnicity, self-reported health, number of ADLs, and poverty status, 1991–1992.

			Under 6 months				6–11 months			
	Population (1000s)	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Population Needing Assistance	3,635	120	415	38	11.4	1.0	322	28	8.9	0.7
Gender										
Male	1,412	66	154	23	10.9	1.6	156	24	11.1	1.5
Female	2,223	93	261	32	11.7	1.4	166	22	7.5	0.9
Age Group										
15–24	90	18	14 *	7	15.7 *	6.7	7 *	4	7.6 *	4.5
25–34	225	31	26 *	9	11.7 *	3.6	23 *	9	10.3 *	3.5
35–44	338	32	59	17	17.5	4.4	17 *	7	5.0 *	2.0
45–54	320	30	19 *	7	5.8 *	2.1	29 *	9	9.2	2.8
55–64	437	41	41	11	9.4	2.6	45	12	10.3	2.4
65–74	729	47	104	18	14.2	2.4	42	11	5.7	1.5
75–84	938	53	114	22	12.1	2.2	83	19	8.8	1.9
85+	556	40	38	10	6.8	1.7	76	14	13.7	2.2
Race and Ethnicity										
Hispanic	141	20	20 *	7	14.2 *	4.4	18 *	8	12.6 *	4.5
Non-Hispanic white	2,896	105	329	34	11.4	1.2	291	27	10.1	0.9
Non-Hispanic black	548	44	59	13	10.7	2.2	12 *	6	2.1 *	1.0
Non-Hispanic other	49	13	7 *	4	14.5 *	7.6	2 *	2	3.5 *	3.5
Self-Reported Health										
Excellent	57	11	9 *	5	14.9 *	8.2	3 *	3	5.6 *	5.4
Very good	142	19	16 *	9	11.1 *	6.5	26 *	9	18.3 *	5.7
Good	491	35	52	13	10.7	2.4	46 *	15	9.3 *	3.0
Fair	1,104	61	128	18	11.6	1.4	75	13	6.8	1.1
Poor	1,840	80	210	27	11.4	1.5	173	20	9.4	1.0
Number of ADLs										
1 of 5	1,487	85	149	23	10.0	1.4	161	22	10.8	1.3
2 of 5	760	50	91	19	12.0	2.4	71	13	9.3	1.6
3 of 5	488	45	68	16	14.0	3.0	29 *	9	5.9 *	1.8
4 of 5	585	46	66	14	11.3	2.3	48	11	8.2	1.9
5 of 5	315	34	40 *	12	12.6	3.5	15 *	6	4.7 *	1.8
Family Income < PL	733	50	78	17	10.7	2.3	63	13	8.6	1.8

Note: Excludes persons whose duration is not reported (weighted number is 41,000 persons).

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

* Estimate has low statistical reliability (relative standard error > 30%).

1–2 years				3–5 years				Over 5 years			
Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
980	67	27.0	1.4	790	42	21.7	1.0	1,128	67	31.0	1.6
319	31	22.6	1.9	308	31	21.8	2.0	474	37	33.6	2.2
661	52	29.7	1.8	481	32	21.7	1.3	654	49	29.4	1.8
10 •	5	11.3	4.8	7 •	4	7.9	4.4	52	11	57.5	7.6
51	13	22.7	5.0	34	9	15.1	4.1	90	20	40.2	5.7
50	12	14.7	3.2	81	16	24.0	4.5	132	20	38.9	4.9
92	17	28.8	4.6	50	11	15.7	3.1	130	21	40.5	5.2
113	18	25.8	3.3	88	18	20.2	3.5	150	23	34.3	4.2
216	27	29.7	3.1	156	23	21.4	2.7	212	29	29.0	3.3
279	37	29.8	3.1	247	28	26.4	2.9	215	27	22.9	2.8
168	18	30.2	2.6	126	19	22.6	3.0	149	22	26.8	3.5
30	7	20.9	4.0	9 •	5	6.2 •	3.5	65	13	46.1	6.5
763	58	26.3	1.5	668	41	23.1	1.3	846	62	29.2	1.8
171	24	31.2	3.8	104	14	18.9	2.3	203	25	37.0	3.3
17 •	9	33.7 •	14.8	10 •	5	19.5 •	9.6	14 •	6	28.8 •	10.1
4 •	3	7.6 •	5.2	10 •	4	18.2 •	6.3	31 •	9	53.8	10.8
19 •	7	13.2 •	5.0	34	10	24.0	6.1	47	12	33.5	7.2
113	19	22.9	3.2	78	17	15.9	3.3	202	20	41.2	3.6
301	36	27.3	2.8	263	29	23.8	2.4	338	37	30.6	3.0
543	42	29.5	1.9	404	30	22.0	1.5	510	48	27.7	2.1
445	51	30.0	2.5	313	32	21.0	1.9	420	38	28.2	2.3
212	24	28.0	2.5	202	26	26.6	2.9	184	27	24.2	3.1
119	24	24.3	4.1	95	18	19.4	3.6	177	32	36.3	5.4
133	23	22.8	3.5	113	22	19.3	3.3	225	33	38.4	4.8
70	19	22.2	5.0	68	16	21.5	4.4	123	18	39.0	4.9
236.6	31	32.3	3.4	138	23	18.9	2.8	217	27	29.6	3.2

Table 2. ADL status of people aged 15 and older, by gender, age, race and ethnicity, marital status, and education level, 1991–1992.

Sociodemographic Group	Mean Adult Age	Population (1000s)	Not Limited				Limited Only				Need Help			
			Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Total	42.6	194,861	187,588	1,625	96.3	0.1	3,597	136	1.9	0.1	3,676	121	1.9	0.1
Gender														
Male	41.6	93,541	90,787	881	97.1	0.1	1,334	80	1.4	0.1	1,420	66	1.5	0.1
Female	43.5	101,320	96,801	837	95.5	0.1	2,263	101	2.2	0.1	2,256	94	2.2	0.1
Mean Adult Age(years)**					41.8	0.1			62.2	0.6			65.1	0.6
Age Group														
15–24	19.6	34,667	34,485	554	99.5	0.1	92	22	0.3	0.1	90	18	0.3	0.1
25–34	29.7	42,646	42,241	524	99.1	0.1	178	26	0.4	0.1	227	31	0.5	0.1
35–44	39.3	39,358	38,686	509	98.3	0.1	331	37	0.8	0.1	341	31	0.9	0.1
45–54	49.2	26,620	25,792	408	96.9	0.2	507	50	1.9	0.2	320	30	1.2	0.1
55–64	59.5	21,032	19,920	402	94.7	0.3	658	52	3.1	0.2	454	42	2.2	0.2
65–74	69.2	18,280	16,691	323	91.3	0.4	848	56	4.6	0.3	741	48	4.1	0.2
75–84	78.8	9,824	8,153	217	83.0	0.7	725	47	7.4	0.5	946	53	9.6	0.5
85+	85.0	2,434	1,620	83	66.6	2.0	258	35	10.6	1.3	556	40	22.9	1.4
Race and Ethnicity														
Hispanic	37.6	10,570	10,285	356	97.3	0.2	145	18	1.4	0.2	141	20	1.3	0.2
Non-Hispanic white	43.5	157,256	151,390	1,549	96.3	0.1	2,941	127	1.9	0.1	2,925	106	1.9	0.1
Non-Hispanic black	39.4	20,187	19,163	520	94.9	0.3	468	44	2.3	0.2	556	45	2.8	0.2
Non-Hispanic other	38.4	6,848	6,750	308	98.6	0.3	44	13	0.6	0.2	54	13	0.8	0.2
Marital Status														
Never married	26.6	51,436	50,612	663	98.4	0.1	375	40	0.7	0.1	449	36	0.9	0.1
Married	46.3	108,140	104,776	968	96.9	0.1	1,544	77	1.4	0.1	1,820	80	1.7	0.1
Widowed	70.3	1,319	11,553	225	84.2	0.6	1,089	64	7.9	0.4	1,077	60	7.9	0.4
Divorced/separated	44.3	21,566	20,648	354	95.7	0.3	588	54	2.7	0.2	330	31	1.5	0.2
Education Level														
Not high school graduate	45.6	43,626	40,374	551	92.5	0.3	1,595	90	3.7	0.2	1,658	79	3.8	0.2
High school graduate	43.2	69,092	66,631	971	96.4	0.1	1,137	58	1.7	0.1	1,324	67	1.9	0.1
Some college	39.0	42,522	41,540	627	97.7	0.1	548	43	1.3	0.1	433	39	1.0	0.1
College graduate	43.6	18,140	17,885	312	98.6	0.2	162	20	0.9	0.1	94	20	0.5	0.1

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

** SIPP recodes all adults over age 85 as 85, so the mean estimates may be artificially low.

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Table 3. ADL status of adults aged 18–64, by workforce participation, work disability, and income status, 1991–1992.

	Total				Not Limited				Limited Only				Need Help			
	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE
Male	73,567	743	100.0	0.0	72,175	724	100.0	0.0	740	61	100.0	0.0	652	52	100.0	0.0
No income	4,626	326	6.3	0.4	4,507	327	6.2	0.4	67	16	9.1	2.0	51	11	7.8	1.5
Working full time	54,838	576	74.5	0.3	54,494	573	75.5	0.3	225	34	30.4	3.4	119	19	18.3	2.7
Working part time	6,035	159	8.2	0.2	5,973	158	8.3	0.2	49	11	6.6	1.5	13 *	6	2.1 *	0.9
Not working	12,694	247	17.3	0.3	11,709	238	16.2	0.3	466	42	63.0	3.2	519	47	79.7	2.8
No work disability	65,280	738	88.4	0.3	65,032	731	89.7	0.2	133	21	17.9	2.6	115	21	17.6	2.9
Limited in amount or kind of work	5,267	168	7.1	0.2	4,911	161	6.8	0.2	246	34	33.3	3.1	110	18	16.9	2.5
Unable to work	3,321	126	4.5	0.2	2,533	105	3.5	0.1	362	37	48.8	3.2	427	41	65.5	3.4
Median Annual Income	$ 21,653	$ 17			$ 21,954	$ 17			$ 12,016	$ 1			$ 9,585	$ 61		
Female	76,793	724	100.0	0.0	75,050	709	100.0	0.0	1,000	66	100.0	0.0	744	55	100.0	0.0
No income	7,476	324	9.7	0.4	7,251	318	9.6	0.4	122	21	12.2	2.1	103	19	13.7	2.5
Working full time	37,579	420	48.9	0.4	37,297	419	49.7	0.4	203	22	20.3	1.8	80	12	10.7	1.6
Working part time	13,457	257	17.5	0.3	13,310	260	17.7	0.3	93	17	9.3	1.7	54	12	7.2	1.5
Not working	25,757	423	33.5	0.4	24,443	414	32.6	0.4	704	56	70.4	2.3	610	49	82.1	2.0
No work disability	68,217	699	88.5	0.3	67,904	697	90.2	0.3	210	23	20.9	1.9	103	20	13.8	2.5
Limited in amount or kind of work	4,780	158	6.2	0.2	4,376	152	5.8	0.2	252	28	25.1	2.3	151	23	20.2	2.5
Unable to work	4,071	134	5.3	0.2	3,034	108	4.0	0.1	542	47	54.0	2.7	494	42	66.0	3.2
Median Annual Income	$ 11,750	$ 9			$ 11,990	$ 6			$ 6,976	$ 42			$ 5,200	$ 23		

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

* Estimate has low statistical reliability (relative standard error > 30%).

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Table 4. ADL status of people aged 15 and older, by family income, 1991–1992.

	Total				Not Limited				Limited Only				Need Help			
	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE	Population (1000s)	SE	% of column population	SE
Family Income < PL	22,579	544	11.6	0.3	21,040	545	11.2	0.3	795	68	22.1	1.5	744	51	20.2	1.2
Annual Family Income																
≤ $5,000	9,343	253	4.8	0.1	8,826	260	4.7	0.1	277	39	7.7	1.0	240	31	6.5	0.8
$5,001–$7,000	5,090	166	2.6	0.1	4,450	152	2.4	0.1	384	42	10.7	1.0	256	31	7.0	0.9
$7,001–$10,000	9,648	273	5.0	0.1	8,709	245	4.6	0.1	532	46	14.8	1.2	408	45	11.1	1.1
$10,001–$15,000	16,899	402	8.7	0.2	15,838	386	8.4	0.2	552	48	15.3	1.3	510	50	13.9	1.2
$15,001–$20,000	17,431	351	9.0	0.2	16,438	338	8.8	0.2	479	41	13.3	1.1	514	40	14.0	1.0
$20,001–$25,000	17,094	364	8.8	0.2	16,437	356	8.8	0.2	282	41	7.9	1.1	375	39	10.2	1.0
$25,001–$35,000	30,546	561	15.7	0.3	29,607	543	15.8	0.3	409	39	11.4	1.0	529	48	14.4	1.3
$35,001–$50,000	35,213	536	18.1	0.3	34,409	532	18.3	0.3	355	38	9.9	1.0	450	44	12.2	1.2
> $50,000	52,964	914	27.2	0.4	52,252	896	27.9	0.4	323	32	9.0	0.8	389	37	10.6	0.9
Median Annual Income	$ 32,244	$ 23			$ 32,857	$ 23			$ 15,686	$ 51			$ 19,272	$ 57		

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

Table 5. ADL status of people receiving program benefits, by age group, 1991–92.

	Total				Not Limited				Limited Only				Need Help			
Benefit Program	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE	Population (1000s)	SE	(%)	SE
Age 15–64	160,943	1,315	100.0	0.0	157,757	1,299	100.0	0.0	1,761	89	100.0	0.0	1,425	78	100.0	0.0
Medicare	2,686	107	1.7	0.1	1,930	83	1.2	0.1	356	35	20.2	1.5	400	39	28.1	2.2
Unemployment	2,724	107	1.7	0.1	2,675	104	1.7	0.1	36 •	14	2.1 •	0.8	13 •	6	0.9 •	0.4
Workers' Comp	839	57	0.5	.	670	49	0.4	.	99	20	5.6	1.1	70	16	4.9	1.1
Medicaid	9,688	292	6.0	0.2	8,854	275	5.6	0.2	372	46	21.1	1.9	462	43	32.4	2.3
Social Security	7,117	206	4.4	0.1	6,013	179	3.8	0.1	568	52	32.3	2.1	536	44	37.6	2.1
SSI	2,444	123	1.5	0.1	1,980	104	1.3	0.1	164	30	9.3	1.5	300	33	21.0	2.0
AFDC	3,432	147	2.1	0.1	3,313	145	2.1	0.1	63	12	3.6	0.7	56	14	4.0	1.0
GA	686	55	0.4	.	646	50	0.4	.	25 •	9	1.4 •	0.5	16 •	6	1.1	0.4
Age 65 or older	28,499	468	100.0	0.0	24,600	429	100.0	0.0	1,724	88	100.0	0.0	2,176	101	100.0	0.0
Medicare	27,839	489	97.9	0.2	24,068	447	97.8	0.2	1,702	83	98.7	0.5	2,120	80	97.4	0.8
Unemployment	39	12	0.1	.	34 •	11	0.1 •	0.1	3 •	3	0.2 •	0.2	2 •	2	0.1 •	0.1
Workers' Comp	46	10	0.2	.	35	10	0.1	.	4 •	3	0.2 •	0.2	7 •	4	0.3 •	0.2
Medicaid	2,294	111	8.1	0.4	1,602	91	6.5	0.4	260	32	15.1	1.7	432	35	19.9	1.6
Social Security	26,434	486	92.8	0.3	22,833	442	92.8	0.4	1,619	78	93.9	1.1	1,982	78	91.1	1.1
SSI	1,670	92	5.9	0.3	1,162	80	4.7	0.3	201	27	11.7	1.5	306	26	14.1	1.2
AFDC	37	11	0.1 •	.	26 •	9	0.1 •	.	3 •	3	0.2 •	0.2	8 •	5	0.4 •	0.2
GA	31	9	0.1	.	16 •	6	0.1 •	.	7 •	4	0.4 •	0.3	8 •	4	0.4 •	0.2

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

Note: Social Security category includes SSDI and survivors benefits for persons under age 65.

• Estimate has low statistical reliability (relative standard error > 30%).

. Standard error is less than 0.05 but greater than 0.00.

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Table 6. Primary source of ADL assistance, by gender, age, race and ethnicity, marital status, and poverty status, 1991–1992.

	Total		Son				Daughter				Spouse				Parent			
	Population (1000s)	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Total	3,676	121	295	31	8.0	0.8	712	43	19.4	0.9	1,398	67	38.0	1.4	201	22	5.5	0.6
Gender																		
Male	1,420	66	99	18	7.0	1.2	112	19	7.9	1.2	780	49	54.9	2.1	102	17	7.2	1.2
Female	2,256	94	195	26	8.7	1.0	600	44	26.6	1.5	618	45	27.4	1.8	99	16	4.4	0.7
Age Group																		
15-24	90	18	–	–	–	–	–	–	–	–	6 *	4	7.1 *	3.9	56	13	62.1	7.6
25–34	227	31	16 *	8	6.9 *	3.2	22 *	8	9.5 *	3.2	80	18	35.2	5.6	66	15	29.0	5.0
35–44	341	31	34	10	9.9	2.8	35	9	10.2	2.3	160	24	46.8	5.0	40	12	11.9	3.2
45–54	320	30	12 *	5	3.9 *	1.6	47	13	14.6	4.1	141	22	43.9	5.1	31 *	9	9.6	2.8
55–64	454	42	50	12	10.9	2.5	55	12	12.2	2.4	209	29	46.1	4.7	5 *	4	1.1 *	0.8
65–74	741	48	61	16	8.3	2.0	134	19	18.1	2.3	374	28	50.5	2.9	–	–	–	–
75–84	946	53	66	14	7.0	1.4	219	28	23.2	2.5	354	38	37.5	3.2	3 *	3	0.3 *	0.3
85+	556	40	55	13	9.9	2.2	201	20	36.1	3.3	73	15	13.1	2.4	–	–	–	–
Race and Ethnicity																		
Hispanic	141	20	10 *	4	7.0 *	3.1	29 *	10	20.5 *	6.3	59	11	41.6	6.1	21 *	8	15.1 *	4.9
Non-Hispanic white	2,925	106	216	25	7.4	0.8	522	39	17.8	1.1		66	41.6	1.7	153	19	5.2	0.6
Non-Hispanic black	556	45	53	11	9.5	1.7	150	21	26.9	3.3	112	16	20.1	2.6	21 *	9	3.8 *	1.6
Non-Hispanic other	54	13	16 *	9	29.5 *	12.7	12 *	4	21.6	6.5	10 *	4	19.0 *	7.2	6 *	4	10.3 *	7.0
Marital Status																		
Never married	449	36	24 *	10	5.3 *	2.2	28 *	9	6.2 *	1.9	3 *	3	0.7 *	0.7	163	20	36.3	3.9
Married	1,820	80	78	14	4.3	0.7	153	22	8.4	1.1	1,379	66	75.8	1.9	21 *	10	1.2 *	0.5
Widowed	1,077	60	139	21	12.9	1.8	435	38	40.4	2.6	8 *	6	0.7 *	0.5	3 *	3	0.3 *	0.3
Divorced/separated	330	31	54	12	16.2	3.4	97	17	29.3	4.5	7 *	4	2.2 *	1.1	13 *	6	4.1 *	1.6
Family Income < PL	744	51	60	14	8.1	1.8	165	23	22.1	2.9	162	27	21.8	3.2	34	10	4.6	1.3

See notes at end of table.

Table 6. Primary source of ADL assistance, by gender, age, race and ethnicity, marital status, and poverty status, 1991–1992, continued.

	Other relative				Friend/neighbor				Paid help				Other nonfamily				Did not receive help			
	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Total	426	36	11.6	0.9	155	25	4.2	0.7	339	35	9.2	1.0	109	21	3.0	0.6	42 *	13	1.1 *	0.3
Gender																				
Male	136	18	9.6	1.2	48 *	15	3.4 *	1.1	82	15	5.8	1.1	52	15	3.7	1.1	9 *	5	0.6 *	0.4
Female	290	32	12.9	1.3	106	18	4.7	0.8	258	32	11.4	1.4	57	14	2.5	0.6	33 *	12	1.5 *	0.5
Age Group																				
15–24	9 *	5	10.4 *	4.7	10 *	6	11.1 *	6.2	4 *	3	4.6 *	3.3	4 *	3	4.7 *	3.4	–	–	–	–
25–34	10 *	6	4.3 *	2.5	12 *	5	5.2 *	2.5	9 *	5	3.9 *	2.2	12 *	6	5.2 *	2.9	2 *	2	0.8 *	0.8
35–44	38 *	12	11.0 *	3.3	11 *	5	3.1 *	1.5	14 *	6	4.0 *	1.9	7 *	4	2.1 *	1.2	3 *	3	0.9 *	0.9
45–54	47	12	14.5	3.5	17 *	7	5.3 *	2.1	14 *	6	4.3 *	1.9	13 *	7	4.0 *	2.1	–	–	–	–
55–64	54	15	11.9	3.1	36 *	11	8.0	2.3	19 *	7	4.2 *	1.6	8 *	5	1.9 *	1.1	17 *	8	3.8 *	1.7
65–74	64	13	8.6	1.7	10 *	10	1.3 *	1.3	67	13	9.0	1.6	20 *	9	2.7 *	1.1	11 *	8	1.6 *	1.0
75–84	108	17	11.4	1.8	52	14	5.5	1.5	102	20	10.8	2.0	33 *	13	3.4 *	1.3	8 *	5	0.9 *	0.5
85+	97	16	17.4	2.4	7 *	4	1.3 *	0.8	111	19	20.0	2.9	12 *	6	2.2 *	1.0	–	–	–	–
Race and Ethnicity																				
Hispanic	6 *	4	4.5 *	2.5	3 *	2	2.2 *	1.6	8 *	4	5.9 *	3.0	5 *	3	3.2 *	1.8	–	–	–	–
Non-Hispanic white	305	31	10.4	1.0	121	22	4.2	0.7	281	33	9.6	1.2	81	18	2.8	0.6	29 *	11	1.0 *	0.4
Non-Hispanic black	112	18	20.2	2.7	30 *	10	5.4 *	1.7	47	13	8.5	2.3	24 *	8	4.3 *	1.3	8 *	4	1.4 *	0.8
Non-Hispanic other	2 *	2	4.3 *	4.0	–	–	–	–	3 *	3	5.7 *	5.5	–	–	–	–	5 *	4	9.5 *	6.7
Marital Status																				
Never married	121	19	27.0	3.7	33 *	14	7.4 *	2.9	51	12	11.3	2.7	15 *	6	3.3 *	1.4	11 *	7	2.5 *	1.5
Married	70	13	3.8	0.7	23 *	8	1.3 *	0.5	42 *	13	2.3 *	0.7	40 *	13	2.2 *	0.7	13 *	8	0.7 *	0.4
Widowed	195	23	18.1	1.9	46	10	4.3	0.9	216	28	20.0	2.4	28 *	9	2.6 *	0.8	7 *	4	0.7 *	0.4
Divorced/separated	40 *	12	12.1	3.3	52	14	15.7	3.8	31	9	9.3	2.6	26 *	9	7.9 *	2.5	11 *	5	3.2 *	1.6
Family Income < PL	106	20	14.3	2.3	54	11	7.3	1.5	108	19	14.5	2.3	45	11	6.0	1.5	10 *	5	1.4 *	0.7

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

Note: Primary source of ADL assistance by recipient type (in thousands).

* Estimate has low statistical reliability (relative standard error > 30%).

– No respondents in category.

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Table 7. Secondary source of ADL assistance, by gender, age, race and ethnicity, marital status, and poverty status, 1991–1992.

	Total		Son				Daughter				Spouse			
	Population (1000s)	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Total	1,515	78	238	26	15.7	1.6	293	33	19.4	2.0	67	16	4.4	1.0
Gender														
Male	526	43	122	19	23.1	3.3	103	19	19.5	3.3	27 *	10	5.0 *	1.9
Female	988	58	116	18	11.7	1.8	190	27	19.3	2.5	41	11	4.1	1.1
Age Group														
15–24	44	13	–	–	–	–	–	–	–	–	–	–	–	–
25–34	99	19	20 *	11	20.3 *	9.5	16 *	7	15.6 *	6.7	2 *	2	1.8 *	1.9
35–44	164	27	30 *	10	18.5 *	5.6	30 *	12	18.2 *	6.4	18 *	10	11.3 *	5.4
45–54	112	15	27 *	9	24.4 *	7.4	34 *	11	30.3	8.2	3 *	3	2.3 *	2.3
55–64	144	21	24 *	8	16.4 *	5.1	32	9	22.4	5.0	18 *	8	12.9 *	5.1
65–74	290	33	74	14	25.5	4.5	57	14	19.7	4.0	11 *	5	3.7 *	1.8
75–84	402	45	36 *	13	9.0 *	3.0	60	14	14.9	3.3	12 *	6	3.0 *	1.5
85+	260	28	26	7	10.2	2.6	65	17	24.9	5.2	3 *	3	1.2 *	1.2
Race and Ethnicity														
Hispanic	40	10	8 *	4	20.4 *	9.6	8 *	4	19.3 *	8.4	4 *	3	8.9 *	6.1
Non-Hispanic white	1,212	69	199	23	16.4	1.8	225	30	18.6	2.2	56	14	4.6	1.1
Non-Hispanic black	231	30	24 *	8	10.4 *	3.7	49	12	21.3	4.3	8 *	5	3.3 *	2.0
Non-Hispanic other	32	10	7 *	4	21.6 *	12.2	11 *	6	35.1 *	15.9	–	–	–	–
Marital Status														
Never married	213	24	3 *	3	1.2 *	1.2	4 *	4	2.0 *	2.0	–	–	–	–
Married	648	50	167	24	25.7	3.5	164	23	25.3	3.0	67	16	10.4	2.2
Widowed	534	38	59	14	11.0	2.5	104	20	19.4	3.4	–	–	–	–
Divorced/separated	120	22	10 *	4	8.1 *	2.9	21 *	9	17.9 *	6.7	–	–	–	–
Family Income < PL	289	31	55	15	19.1	4.4	73	16	25.4	4.3	–	–	–	–

See notes at end of table.

Table 7. Secondary source of ADL assistance, by gender, age, race and ethnicity, marital status, and poverty status, 1991–1992, continued.

	Parent				Other relative				Friend/neighbor				Paid help				Other nonfamily			
	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE	Population (1000s)	SE	% of row population	SE
Total	89	14	5.9	0.9	371	38	24.5	2.3	93	16	6.2	0.9	274	37	18.1	2.1	90	20	5.9	1.3
Gender																				
Male	51	11	9.7	1.9	85	17	16.1	3.1	28 *	10	5.3 *	1.9	74	17	14.0	2.9	38 *	12	7.2 *	2.2
Female	38	9	3.8	1.0	286	31	28.9	3.0	65	14	6.6	1.3	200	30	20.3	2.6	52	16	5.3	1.5
Age Group																				
15–24	26 *	9	59.0	12.1	5 *	3	10.8 *	6.1	8 *	5	17.6 *	10.4	–	–	–	–	6 *	4	12.6 *	8.6
25–34	29 *	10	29.7	7.4	16 *	7	15.8 *	6.8	3 *	3	3.1 *	3.1	5	0	5.1	1.0	8 *	5	8.5 *	4.9
35–44	21 *	8	12.7 *	4.8	35 *	11	21.1	5.6	9 *	5	5.4 *	3.1	11 *	5	6.6 *	3.1	10 *	8	6.2 *	4.5
45–54	9 *	5	7.7 *	4.7	10 *	5	9.3 *	4.3	13 *	6	12.0 *	4.7	16 *	6	14.0 *	5.8	–	–	–	–
55–64	–	–	–	–	38	11	26.1	5.7	9 *	5	6.2 *	3.2	21 *	8	14.6 *	4.9	2 *	2	1.3 *	1.4
65–74	4 *	4	1.3 *	1.3	45	11	15.4	3.6	21 *	8	7.1 *	2.7	51	15	17.6	4.3	28 *	12	9.6 *	3.8
75–84	–	–	–	–	135	27	33.5	5.2	25 *	8	6.2 *	2.0	105	24	26.1	4.9	30 *	11	7.4 *	2.7
85+	–	–	–	–	88	16	33.9	5.1	6 *	4	2.3 *	1.6	65	13	25.1	4.8	6 *	4	2.4 *	1.7
Race and Ethnicity																				
Hispanic	2 *	2	5.5 *	5.4	10 *	4	24.2 *	9.1	5 *	4	12.1 *	8.1	2 *	2	5.0 *	4.6	2 *	2	4.6 *	4.6
Non-Hispanic white	71	12	5.9	1.0	275	31	22.7	2.4	78	15	6.4	1.1	237	34	19.5	2.4	72	18	5.9	1.4
Non-Hispanic black	15 *	8	6.6 *	3.3	78	18	33.8	5.9	11 *	4	4.7 *	1.8	32 *	11	14.0	4.0	14 *	6	5.9 *	2.6
Non-Hispanic other	–	–	–	–	8 *	5	24.9 *	12.2	–	–	–	–	3 *	3	9.5 *	8.5	3 *	3	8.9 *	8.6
Marital Status																				
Never married	64	12	30.2	5.3	71	18	33.5	6.6	18 *	8	8.5 *	3.6	34	9	16.1	3.9	18 *	7	8.6 *	3.3
Married	16 *	7	2.5 *	1.1	72	18	11.1	2.6	24 *	8	3.7 *	1.2	99	21	15.3	2.9	39 *	13	6.1 *	2.0
Widowed	–	–	–	–	195	24	36.6	4.3	38	10	7.2	1.9	121	22	22.6	3.7	17 *	11	3.3 *	2.0
Divorced/separated	8 *	6	6.7 *	4.5	32	10	27.0	6.8	13 *	6	11.0 *	4.1	20 *	11	16.9 *	8.1	15 *	7	12.4 *	5.2
Family Income < PL	–	–	–	–	60	13	20.7	4.6	31 *	10	10.8 *	3.5	–	–	–	–	34 *	12	11.8 *	3.7

Source: 1990 and 1991 SIPP Core Survey and Topical Module on Functional Limitation and Disability.

* Estimate has low statistical reliability (relative standard error > 30%).

– No respondents in category.

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Appendix A—Variable Definitions

This study is based on disability data from the SIPP topical module on functional limitation and disability, as well as on sociodemographic and socioeconomic variables from the core survey. The topical module on functional limitation and disability consists of a battery of questions on health status, functional limitation, and ADL limitation. The following subsections define the variables employed in the analysis.

DISABILITY VARIABLES

ADLs

SIPP respondents are asked whether they have difficulty with the following ADLs: eating, dressing, bathing, transferring, and toileting. These activities constitute the primary focus of this analysis. The adult population is broken into three major categories: not limited in ability to perform ADLs, difficulty in performing one or more ADLs, and needing assistance to perform one or more ADLs. For the program eligibility analyses, the assistance category is further broken down by number of ADLs (needs assistance with 1, 2, 3, 4, or 5 of 5).

Work Limitation

Interviewees aged 16 to 67 are asked whether a physical, mental, or other health condition limits the kind or amount of work they can do. If they answer affirmatively, they are considered to have a work disability; a follow-up question asks whether this condition prevents them from working.

Health Conditions

If a limitation in capacity is indicated, respondents are asked to identify the conditions or impairments causing that limitation from a list of aggregated International Classification of Diseases (ICD) codes. A separate set of probes is used to identify cognitive impairment (learning disabilities, mental retardation, mental illness, developmental disabilities, senility or dementia).

Duration of ADL Assistance

The duration of ADL assistance is reported in one of the following categories: less than six months, six to twelve months, one to two years, three to five years, and over five years.

Sources of ADL Assistance

Those who say they have difficulty with any ADLs are asked whether they require the assistance of another person. Assistance is not explicitly elaborated to include supervision or standby help. Persons who need ADL assistance are asked to identify the primary and secondary sources of that assistance from the following list: daughter, son, spouse, parent, other relative, friend or neighbor, other non-relative, and paid help. A follow-up question asks about out-of-pocket assistance expenses for individuals or families.

SOCIODEMOGRAPHIC AND SOCIOECONOMIC VARIABLES

Age Group

Age is broken down into ten-year intervals for most analyses (15–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75–84, and 85 and above). The SIPP recodes ages 85 and over as 85 in the public use files, so there is bias that slightly reduces the mean age estimates.

Program Participation

Federal program participation is based on reported receipt of benefits in the reference month.

Income

For reporting purposes, monthly income is multiplied by twelve to derive an annual figure. Family income is assessed in two different ways: counting transfer income, for descriptive analyses, and omitting transfer income, for program eligibility estimates. Negative income—for

example, depreciation of property or assets or lost rental income—was reported by a few families. Because this indicates significant asset ownership, it is deemed a poor indicator of poverty status and is omitted from both family income variables.

RECOMMENDATIONS FOR IMPROVING ADL ASSISTANCE DATA IN THE SIPP

The SIPP should be able to aid federal program planning efforts, but the Topical Module on Functional Limitation and Disability at times falls well short of that objective with regard to personal assistance needs. There are a variety of changes that would clarify the source, type, and amount of assistance that people with ADL limitations need or receive. For example, the category of non-relative is broken down to "friend or neighbor," "paid help," and "other non-relative," apparently assuming that the only people that will get paid for PAS are neither friends nor neighbors nor relatives. Yet a number of state programs, including California's In-Home Health Services program, which has the largest caseload in the United States, allow for payment of relatives (Stone & Keigher, 1994).

The disallowance of paid family members may account for the fact that a third of those respondents with ADL limitations who identified out-of-pocket expenditures did not list a paid provider as a primary or secondary source of assistance. Both the question about out-of-pocket costs and the follow-up, "How much was paid for such help in the past month?," have very low response rates, possibly suggesting some confusion on the part of respondents. A more useful approach may be to decouple payments from assistance categories and include a series of follow-up questions: "Is your helper paid for this assistance?," "Who pays?," and "How much?"

The assistance category, "does not receive help," is particularly problematic. The purpose of this item (and a similar one in the National Long-Term Care Surveys) is unclear. The prevalence of this response type was so low that it was dropped from published analyses. If it was intended to identify unmet need (those needing services but failing to receive them), it clearly failed in isolating a distinct population. A more direct question, such as, "Do you receive as much help as you need?," would presumably yield a more comprehensible measure of the availability and adequacy of current supports.

If the item was intended to serve as a rudimentary validity check (of whether people who say they need the assistance of another person can actually identify that person), then the low prevalence can be seen as a positive finding. More generally, the low response rate for this item suggests that most people living in the community who need help with ADLs get help, although it says nothing about the direct public and indirect private costs of providing this support.

Finally, the key issue for planning purposes that was not addressed in the SIPP is an estimate of the actual amount of hours of assistance received. There is no reason that the questionnaire could not have included a follow-up item for people reporting need for assistance, asking, "How many hours of help did you receive in the past week?" Any meaningful cost projections are impossible without such basic utilization data.

Appendix B—Comparability of ADL Estimates

The Appendix Table contrasts the ADL estimates for the noninstitutionalized elderly population from the 1990 and 1991 SIPP with similar estimates derived from other health surveys. This comparison builds on the work done by the Brookings Institution (Wiener & Hanley, 1990) for the Federal Interagency Forum on Aging-Related Statistics. Data from the National Long-Term Care Survey, the National Health Interview Survey Supplement on Aging, and the National Medical Expenditure Survey are extracted from their comparison tables. The SIPP estimates are roughly comparable to those derived from other national surveys. The total population estimates are somewhat higher, but much of this difference can be attributed to the growth in the elderly population over the period between national surveys.

The total SIPP ADL estimates are quite similar to the 1984 National Long-Term Care Survey estimates used in other published eligibility analyses (Stone & Murtaugh, 1990; Jackson, Burwell, Clark, & Harahan, 1992; Spector, 1991; Spillman & Kemper, 1992). The rates of assistance needed for toileting and eating are somewhat lower in the SIPP, and this may be due to the supervision probes employed in the NLTCS.

The ranking of ADLs is comparable across surveys as well. Bathing is the most common task in which assistance is required, followed by dressing and transferring. Eating is the least common ADL in which assistance is needed, and the prevalence of this ADL is so low it is omitted from the NMES.

Appendix Table. Comparison of National Survey Estimates of ADL Assistance Needs, by ADL Type, for Noninstitutionalized Adults Age 65 or Older.

	1982 National LTC Survey		1984 National LTC Survey		1984 Supplement on Aging		1987 National Medical Expenditure Survey		1991–92 Survey of Income and Program Participation	
	Population (1000s)	(%)	Population (1000s)	(%)	Population (1000s)	(%)	Population (1000s)	(%)	Population (1000s)	(%)
Total	25,440	100.0	26,481	100.0	26,268	100.0	27,909	100.0	30,537	100.0
Needs help with:										
One or more ADLs	1,992	7.8	2,062	7.8	1,318	5.0	2,250	8.1	2,243	7.4
Bathing	1,609	6.3	1,660	6.3	1,211	4.6	1,926	6.9	1,813	5.9
Dressing	1,072	4.2	1,063	4.0	771	2.9	1,228	4.4	1,275	4.2
Transferring	1,072	4.2	1,072	4.0	675	2.6	977	3.5	1,151	3.8
Toileting	857	3.4	880	3.3	619	2.4	670	2.4	766	2.5
Eating	624	2.5	618	2.3	183	0.7	†		337	1.1

Source: Modified from Wiener & Hanley (1990). Measuring the activities of daily living: comparisons across national surveys. Journal of Gerontology, 45(6), p. s234.

† Cell size too small for reliable estimate.

U.S. DEPARTMENT OF EDUCATION
WASHINGTON, D.C. 20202-2646

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